

For how long will my samples be stored?

Your samples will be stored until they are used in research. Non-identifiable images and clinical information may be made available indefinitely for research and education purposes.

Will I know when my samples are being used in the future?

You will not be contacted when your samples are used, however you can obtain information on research conducted on samples stored in the HSA Biobank at this website: www.tcrn.unsw.edu.au/hsa

Research findings will be published in medical and scientific journals and presented at conferences. Findings will always be provided in such a way that you cannot be identified.

Similarly, research is conducted in such a way that individual results generally cannot be returned to participants.

Will drug or biotechnology companies be able to use my samples for profit?

Research involving your blood or tissue samples may result in a product or treatment that is profitable for a company. You will not receive any financial benefit from discoveries arising from the use of your samples or data.

What happens if I suffer injury or complications as a result of the HSA Biobank?

There is no physical risk in collecting tissue for the HSA Biobank beyond that of your hospital procedure. The collection of a blood sample will occasionally cause bruising. Any injuries or complications suffered as a result of the negligence of any parties involved in the HSA Biobank may entitle you to compensation; the cost of your treatment would be paid out of such compensation.

How can I get further information?

If you have any questions about the HSA Biobank, please contact us through the UNSW Biorepository at:

E: biorepository@unsw.edu.au

T: +61 2 9065 5665

Additional information can be found at www.tcrn.unsw.edu.au/hsa

At your request we will print this information for you.

Thank you for taking the time to consider participating in the HSA Biobank.

If you wish to take part, please sign the associated consent form.

This information brochure is for you to keep.



The HSA Biobank has been approved by the South Eastern Sydney Local Health District - Northern Sector Human Research Ethics Committee. Any person with concerns or complaints about the conduct of the HSA Biobank should contact the Research Support Office on: 02 9382 3587, or email: seslhd-rso@health.nsw.gov.au and quote reference number 11/160.

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The HSA Biobank

*Banking today for better
health outcomes*

Patient Information Brochure

Contact: 02 9065 5665

What is the HSA Biobank?

The Health Science Alliance (HSA) Biobank is an initiative of the Translational Cancer Research Network, developed through a partnership between UNSW Australia and NSW Health.

A biobank is a collection of human samples such as tissue and blood, linked to patient information, which is stored and made available to researchers, now and into the future.

The HSA Biobank will provide a valuable resource to researchers and teachers, so that they can increase our knowledge and understanding of disease. The HSA Biobank will enable high quality medical research, leading to better health outcomes for all.

What are we requesting from you?

We are asking you to give consent for the collection of a sample of your tissue, blood or fluid and associated clinical data for storage in the HSA Biobank. Your consent to the HSA Biobank would mean that your specimens and health data are stored for use in future research and education.

Please read this Patient Information Brochure carefully. Feel free to ask questions and to discuss the HSA Biobank with a relative, friend or your local health care worker.

Once you understand what the Biobank is about and you agree to take part, you will be asked to sign a consent form.

Do I have to consent?

Participation is voluntary. You can withdraw at any time by contacting the HSA Biobank. If you decide to withdraw, your samples and collected health information will be destroyed.

Your decision to say no or withdraw consent will not affect your medical treatment or your dealings with Medicare Australia.

What does consent involve?

If you give your consent, the following will be collected:

- A small piece of tissue and/or fluid from the sample removed during your procedure.
- A blood sample or a mouth swab/saliva sample.

If you have had a prior operation that relates to this procedure, we may also access this tissue. If you have another operation in the future within this Local Health District, signing the HSA Biobank consent form will also allow collection of tissue from that procedure.

The HSA Biobank will also request access to relevant health information about you from the following possible sources

- Hospital, pathology, emergency department records.
- State and national databases such as: Admitted Patients Data Collection; Registry of Births, Death and Marriages; and the NSW Cancer Registries.
- Medicare Benefits Scheme records (your visits to health professionals) and the Pharmaceutical Benefits Scheme (your use of prescription medicines)

What will happen to my samples and data?

Your samples and health data will be stored in the UNSW Biorepository at the University of New South Wales until they are requested for research or education. Future research will examine causes of disease, prevention, diagnosis, treatment and genetics. Future education will involve teaching medical, science and nursing students.

All future projects must be approved by a Human Research Ethics Committee before access to your samples or data can be granted.

Will users know my name and identifying details?

No. Your samples and other information will be given a unique identification code used by researchers, teachers and students. Your name and identifying details will be in a separate file that is not available to others. This maintains your confidentiality. All information is stored securely.

